

THE SELF-DETERMINATION CIRCLE

– for an independent life within the community

Material for a study circle concerning human rights in
accordance with Article 19 of the Convention on the Rights of
Persons with Disabilities

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Foreword

The United Nations Convention on the Rights of Persons with Disabilities became legally binding for Sweden in 2009. Article 19 of the Convention concerns the right to a life with self-determination within the community.

- What does this mean for you, in real terms?
- Has the Convention now become a law?
- Must all decision-makers and authorities in Sweden comply with the requirements of the Convention or not?

You and other interested parties can find the answers to these questions and more as part of a mutual learning process using this study material. The study material was written as part of the *Artikel 19 som verktyg* project – a project operated by Independent Living Institute, with financial support from Arvsfonden.

The material you are reading concerns the right to a life with self-determination within the community for all persons with disabilities, and is based on Article 19 of the Convention on the Rights of Persons with Disabilities. The Convention is an international agreement concerning the human rights of persons with disabilities. The study material also uses information from General Comment No 5, which was written by the UN Committee on the Rights of Persons with Disabilities as an explanation of how the rights in the Convention are to be realised in all countries that are involved in the agreement.

The study material has mainly been produced as a guide for the leader of the circle, but it can also be used by those taking part. It includes a description of the study circle method, which builds upon mutual collaboration whereby each person in the circle contributes with their own life experience and knowledge. The learning process is unique for every group, reflecting the different people that are involved and how the study material is used. A summary of the content of General Comment No 5 is included as an annex to the study material. The material features eight exercises that can be used as part of the work within the study circle. It also includes examples of the agendas of and invitations to a study circle that was led by the project.





The intention is that the material will be used as a toolbox and serve as a source of inspiration. You can read all of the material from cover to cover, or just focus on those parts that are of greatest relevance to your particular study circle. The first part of the study material provides general advice on how to conduct a study circle. This is followed by a few tips, including examples that the leader can use when conducting this particular study circle. The most important thing is that the participants work together in a supportive atmosphere and as part of a mutual learning process. This allows everybody to learn something new about their rights in accordance with the Convention, and to make better use of their right to self-determination within the community.

Good luck!

The *Artikel 19 som verktyg* team

Part 1: General information about study circles

What is special about study circles?

All individuals have different life experiences. The question is how to share these experiences with others in order to enable mutual learning. In the grass-roots movements of the nineteenth century, people took the initiative to come together to form study circles. Study circles are not led by teachers with superior knowledge. It is however important for somebody to ensure that the discussion follows a structure, so that everybody is given the opportunity to speak. If the name ‘study circle’ is felt to be too stuffy or old-fashioned, an alternative name can be used. Here we present the basic ideas of the study circle methodology, and these are very important.

This study material represents a foundation that will enable the leader to create a good study circle structure based on the wishes and preferences of the group members. It may also be used as a direct source of support for individuals or groups that wish to learn more about the topic of agency and self-determination. However, many of the questions are general in nature and are also suitable for use in circles addressing other topics.

In regular education individuals learn on their own, but the idea of study circles is that the group learns together. Participants make progress and gain new insights as a group. A study circle involves the exchange of experiences and participants learn from each other by means of conversation. These discussions raise new questions that can provide inspiration for continued investigation. The study circle can become a source of rewarding discussions generating new perspectives and insights for issues in ways that don’t ordinarily happen during planning days or conversations during coffee breaks.

Each participant must be given the chance to share their own thoughts and experiences, but without feeling pressured to talk about private matters or anything else they would rather not discuss. Of course, the information people share needs to be true. Discussions shall be held in a spirit of openness, honesty and, ideally, inquisitiveness.



The study circle also enables empowerment, where every participant is given the chance to make themselves heard and to contribute with their own experiences and ideas. Comparing one's own thoughts with those of others leads not only to an understanding of others' situations but also of one's own – it can be seen in a wider context, highlighting differences and similarities.

As a matter of principle, participation in a study circle is always voluntary. Naturally, the working method can also be used for other purposes, such as the mandatory further training of staff, but in those cases it should be given a different name.

It can sometimes be difficult for people to meet in person on a regular basis. The study material can also be used when conducting a digital study circle using video meetings or different forms of chat groups, but there is something special that happens when people meet with each other in person.

Learning from each other

Regardless of whether the study circle is conducted in person or online, the purpose is for participants to learn from each other. Most will have worked in groups before, and will know that there are both advantages and disadvantages. The division of work can sometimes be unclear, which means that some people end up doing more than others, but it can also be that the team spirit and the sense of working to the same purpose mean that the group begins to work like a finely tuned team. The results of the mutual work somehow become greater than the sum of each individual's efforts.

There seems to be a universal rule that dictates the size of those groups that work well together. A group of between five and eight people is the optimum size for ensuring a good, creative dynamic. A group of three or four people is too small for any dynamic discussions to arise, although it can, of course, work well as a group working with a specific assignment. If the group is larger than eight people, subgroups and unequal power distribution can easily develop. Some members may perhaps find it uncomfortable to speak in such a large group, and the room left by their silence will be filled by others who have better leadership qualities.

One factor that is important for the circle leader to bear in mind is whether the group members already know each other – this situation has both advantages and disadvantages. It may also be the case that certain members know each other, whilst others do not. One advantage of already knowing each other is that the path that leads to the group engaging in deep discussions can be shorter. However, there is also a risk of falling into established habits, and continuing to talk in the same way as they would during a coffee break, for example. If a study group comprises a previously established team, it is therefore important that the participants view the study circle as something different to their usual interaction at work.

Collaboration is a key aspect of human activity, and we are often happiest when we're together with others, whether this is socialising at a party, on an excursion or as part of a healthy work environment. When we begin to be part of a group, our first reactions are to try to establish what kind of a group it is and who the other group members are. This initial hesitant phase is usually followed by a pleasant feeling of community and belonging. Paradoxically, there is also a risk involved in remaining in this contented phase; after all, the purpose of a study circle is not for participants to enjoy themselves and to forge life-long relationships, but to listen and learn from each other in a reflective and constructive manner.

Sometimes, it is friction and differences of opinion that propel the group forwards. Do not be afraid of these, and resist the temptation to try to ignore them (as we in Sweden are often inclined to do). Instead, allow the differences of opinion to enrich the discussion and to stimulate its progress. Even conflict can have a developmental effect if the causes of the conflict can be identified and resolved. Everybody arrives with their own psychological baggage, and all these unique experiences and differing opinions are worth exploring and exploiting.





Preparation

One role of study associations is to help to arrange study circles, but this is also a form of work that can be organised independently. You can start by considering which financial and practical resources will be available for the study circle. Do you have access to physical premises or a digital meeting platform? Will you want to include coffee breaks, and will you have the opportunity to cater for these? Will you need to purchase pens, pads or any other materials? Once you know which resources you do and do not have, you can begin to think about solutions. One solution could be to initiate a collaboration with a study association, an interest group dedicated to disability rights or another organisation that can help to provide you with premises or a digital meeting platform. Pens, paper and refreshments can be organised as a collaborative project among the group members, or you could ask each participant to bring their own.

The initiative to form a study circle can have various origins, but there will often be a need for some form of invitation and a considered strategy in order to recruit participants. It then becomes important to have clarity concerning the purpose of the study circle, to prevent the risk of misunderstandings and disappointment. Discuss the purpose of the group, the expectations of the individual group members, and what they will be expected to do and read in the time between the initial meetings. Decide in advance how many meetings there will be (e.g. five or six), as well as the location, dates and times. The optimum length of each meeting is around 1.5 hours, including a break for a rest and toilet visits, etc. The times and number of meetings can be a subject for discussion at the first meeting, and can be changed if the majority of the group members feel it is necessary. After the first meeting, however, it is not a good idea to change the meeting times or locations.

At the start of the study circle, it is important to explain the values and rules of the group. Each group must work together to establish the rules of order for their study circle, but all circles must involve respect for each other's opinions, and a zero-tolerance approach to personal attacks and to speaking derogatorily about others – whether they are present or not. Talk to each other, not about each other! One good piece of advice is... do not give advice! Trying to guide people in a certain direction and offering patronising tips are not as popular as some people seem to think. It is better to encourage each group member to talk about their own experiences and how they resolved different situations. Then allow everybody to draw their own conclusions.

The composition of each group of people is unique. It is possible that the circle leader will not know much about the participants until they meet. It is therefore important to provide the opportunity for them to be informed of any special needs in advance. Any accessibility requirements must be considered, in order to prevent the risk of any person becoming excluded. A few examples of things to consider with regard to the premises are presented below.

The premises must be accessible by a lift and have automatic door openers. The light must neither be too bright (e.g. large windows) or too dark. The room's acoustics can be improved using sound-absorbing textiles, etc. Check whether the room has an audio loop or if there is a need for one. Portable audio loops can sometimes be hired or loaned. Bear also in mind that cluttered or sensory-rich environments can be disruptive – particularly for this type of discussion.

It may be the case that not all requirements can be satisfied. If a situation arises whereby any participant has a need for a particular accessibility measure, it is important to try to find solutions. In addition to issues concerning the premises, there may be other accessibility considerations that are relevant in the study circle. There may also be requirements that concern cognitive accessibility – for example, text material that the group is to work with must be produced in such a way that all participants will be able to understand it. The group must identify its own tempo that all members are able to keep up with. In early meetings, certain people may find it frustrating when they are not able to conduct discussions or perform exercises at their accustomed fast pace. But this does not have to be a problem. This can be seen as an experiment to create completely accessible environments. This is ultimately what we are aiming to achieve when we talk about a fully inclusive society. Society is to be organised so that every individual can be involved everywhere, irrespective of any accessibility requirements. Why not discuss how a universally adapted meeting culture can contribute to the realisation of every individual's right to be included in society.



Leading the conversation

The person who leads a study circle does not need to know more than the other participants about the subject being addressed, but does need to ensure that the group's discussions begin and end at the designated times. Even if the circle leader is not a teacher, this does not mean that there is no need to make any preparations. Before each meeting, consider the topic to be addressed and think about how you think the conversation will develop, and which questions and issues are likely to arise, etc.

If the meeting is held in person, it is important to arrive early and ensure the room is in order. Rearrange the furniture to ensure there are the right number of chairs – either at a desk or perhaps in a circle. Arrange bottles of water or any other refreshments. It is essential that you test any digital tools in advance, such as projectors, etc. Projectors and/or shared digital documents can be used, but a good old-fashioned flipchart or sheet of paper on the desk can also work just as well (sometimes even better) to help make sense of the discussion, while also serving as documentation when reviewing the session. Remember to always read out what has been written, and describe the content of visual images.

Begin by welcoming everybody to the study circle. At the first meeting, invite all members to take it in turns to introduce themselves. Help things along by asking a specific question, such as:

- what is your greatest interest?
- what makes you happy?
- what is something you would like to change?
- what makes you angry?
- when are you at your most content?
- who is your personal role model?
- what does injustice mean to you?
- If any additional member joins the study circle at a later date, you will need to conduct a new round of introductions so that the new member can feel included in the group.

You can also take newspaper clippings of pictures or postcards depicting different themes. Spread the pictures out on a table and ask the participants to choose one picture that represents how they feel. Invite the participants to introduce themselves and explain why they chose that particular picture.

Later meetings should open with a quick opportunity for the group members to take it in turns to briefly say something about their current situation. It is also a good idea to begin by referring back to the previous meeting. Ask, for example, whether they have thought any more about what was discussed last time.

In addition to ensuring that times are adhered to, the circle leader shall also drive the conversation forwards. Each group member must be able to share their thoughts, so it may sometimes be necessary to ask a more talkative member to wait and give one of the quieter members the chance to speak. If you notice that such a situation has arisen in your group, one tip is to pause the discussion and carefully explain that from now you will be actively inviting individuals to speak in order to ensure that everyone has the same chance to express themselves. You are not doing this because what the more talkative members are saying is not important; you are doing it to ensure that each group member is able to share their experiences and knowledge in the discussions. When you need to actively allocate the chance to speak, it is important that you make it clear that you are not trying to suppress anybody's contribution to the discussion, but that you are doing it to ensure greater equality of expression. A general rule of thumb is for the circle leader to manage the meeting by interrupting a person who has been talking for too long, and to invite one of the quieter members to speak instead (who is, naturally, not obliged to speak). The leader must pay attention to ensure that nobody is neglected or made to feel inadequate. It can be a good idea to read about methods people use to dominate situations, in order to prevent this from taking place. If a certain topic keeps coming up, time and again and in the same way, or if the discussion strays too far away from the intended subject, it is the responsibility of the circle leader to gently, but firmly, redirect the nature of the discussion to get it back on track.

Wind up in plenty of time before the end (around 10 minutes), summarise what has been said, and hand out any material that is to be studied before the next meeting. The circle leader can do this, but this could also be delegated to other participants. Save time for a brief evaluation, thank the group members for their participation, and remind them of the time for the next meeting. Then tidy the room and gather together all the materials and documentation.



Distribution of power

The individuals that form the group will determine how the conversations take shape. The larger the groups, the more important it becomes to ensure that all group members have an equal opportunity to express themselves. There may be several differences in the members' strengths and backgrounds, such as age, gender, gender identity or expression, sexual orientation, ethnicity, religion or other beliefs, education, occupation, disability, etc. The presence of a manager in the same group as those who work under him/her can also have an impact on the conversation. The same also applies if close friends or relatives are included, but the greatest factor is usually the different personalities within the group. Sometimes, a dominant person must be held back in order to allow quieter members to become involved.

If a study circle is held at a place of work, this should of course be approved by the appropriate manager. It is also important to be aware of the mandate the group has. It may be that the group has been tasked with developing new ideas and proposals that will subsequently be processed and realised. It could also, of course, be the case that the group has no mandate at all. This can lead to frustration, if the group is trying to come up with solutions that they know will never see the light of day. However, the discussions in a circle without a mandate can fulfil an important purpose of reflection and understanding, which also leads to dividends in the longer term.

Influence and impact can be achieved in many ways, from informing others of one's situation to coming up with suggestions and advice, or even by being involved and taking responsibility for decisions and results. What is important is to discuss and make it clear from the beginning what function the study circle is to have.

Even in local clubs and associations, segregation on the basis of disability is still a factor – the visually impaired socialise with others who are visually impaired, those with dyslexia associate with others with dyslexia, etc. It remains rather unusual to have a group where the participants have wildly different levels of ability/disability. Can people with mental disabilities, for example, participate in a study circle? In our experience, this can work well, but it is still necessary to ensure respect and understanding for each other's different conditions and abilities.

One way to introduce new aspects into the conversation without them taking over could be to invite a guest to one of the meetings. This could be a researcher, a lawyer, or anybody with interesting experiences of living with disability, who you would like to have as a source of knowledge and inspiration but who will not be a permanent participant in the group.

There are many ways to identify and work with power relationships within a group. One way to identify inequality – and to get a sense of what it feels like – is to conduct a simple role-play exercise. Come up with an appropriate situation where the participants can adopt different roles, such as a case worker at the social security office, an applicant for a job or a worried parent.



Advice for digital study circles

- Most people have little or no experience of using a digital meeting format. This can cause some people to worry that they will not be able to participate in a digital meeting. Using this format can be confusing, so it is important to **ensure that the first digital meeting will, in technological terms, be as simple as possible for people to join in and to feel that it is a viable option.** It is also important to send clear instructions for how participants are to join the digital meeting, and how they can get help if they need it. It is important to provide support and to encourage all members of the study circle to give the new meeting format a chance.
- There are many different platforms available that can be used for holding digital meetings. When choosing one of these platforms, you should **test different meeting platforms** in order to determine which will be easiest to use for your participants. The objective is for you to identify the platform that makes it as easy as possible for participants to join the meeting, and where the use of the functions that the participants will need is as clear and intuitive as possible.
- Once you have booked a meeting via a platform for webinars, it is important that you are able to provide **step-by-step instructions** that participants can follow in order to join the meeting. Bear in mind that, from a technical point of view, your user experience of the platform as a ‘host’ will be slightly different to that of the other participants. In order to be able to give step-by-step instructions, therefore, you must find out how the platform will work from their perspective. One way to do this is to open your web browser in ‘incognito mode’, and open the meeting’s URL address without your computer recognising who you are.
- It is important to be prepared to offer a lot of **IT support** for your group, to ensure that everybody manages to join and actively participate in the digital meeting. It may be a good idea to send an email containing step-by-step instructions for how to join the digital meeting. You can also call all participants in the week before the first meeting, and talk each of them through the process individually. You can then call everyone again on the day of the meeting, to provide help with any technical problems that may arise at the last minute.

- If you call the participants and they are experiencing difficulties in joining the meeting, you can open your own web browser in **'incognito mode'** again and see how the process looks from the participant's perspective. This can make it easier for you to understand why they are finding it difficult, and identify how the problem can be resolved.
- You should be aware of the fact that the participants may experience problems with their technology at home. You should then be prepared to be able to offer the participants (and help them with) **alternative methods of being able access the meeting**, such as the option of connecting via a telephone call, or using the 4G network if there are problems with their home broadband networks, etc.
- It is useful to plan your digital meeting so that the participants are able to test the technology in plenty of time before the meeting is due to begin. You can also encourage them to test whether it is working a few days before the meeting. Then, if somebody is experiencing problems, you will have time to resolve them before the meeting begins. **You should ideally open the digital meeting up to 45 minutes before the official start time, so that everyone has the chance to try connecting to the meeting and to test their technology before it begins.** After these 45 minutes, you should have resolved any technical issues that have arisen, and can begin the meeting on time.
- At the beginning of the meeting, it can be a good idea to explain to the participants how they can turn their microphones and webcams on and off, how the chat function works, etc., so they will be able to control what others will see and hear of them. Remember that you, as 'host', are also able to turn off the microphones of all participants. It is recommended that you learn how to use this kind of function, so that you can turn off any disturbing noises that somebody may make.
- The circle leader should consider making contact with a study association to find out which digital meeting platform(s) they use. There may be certain limitations that apply to which digital meeting platforms a study association is able to use or recommend.



Part 2: About the self-determination circle

The United Nations and human rights

Global developments over the past few hundred years have resulted in the formation of states and the need for them to interact with each other. Even since before the formation of the nation states as we now know them, relationships have existed between countries, and many different agreements have been reached to regulate their mutual relationships. More highly developed, intergovernmental agreements are often referred to as pacts or treaties.

The United Nations (UN) was formed after the end of the Second World War in 1945, and is today an international intergovernmental organisation of which almost all of the world's countries are members. The UN operates according to the concept of universal human dignity, rights and freedoms. Since the formation of the UN, human rights have developed to keep pace with the development of societies.

The fundamental human rights are stipulated in many different documents – many of which are international treaties. What we refer to as conventions are international treaties that result in those states that are signatories and that ratify them (i.e. that undertake to comply with them) being legally bound in the sense of public law by the content of the convention. Accordingly, these states must do certain things in order to fulfil their international obligations.

A convention is a document that, in many ways, resembles a legislative text. It is, however, important to remember that these are international agreements between states, which means that they must be read in a slightly different way than legislation that is designed to only apply within one country.

There are several conventions that are usually regarded as constituting the core of human rights regulations within the UN. These are:

The Convention on Civil and Political Rights

- The Convention on Economic, Social and Cultural Rights
- The Convention on the Elimination of All Forms of Racial Discrimination
- The Convention on the Elimination of All Forms of Discrimination Against Women
- The Convention on the Rights of the Child
- The Convention on the Rights of Persons with Disabilities
- The Convention on Protection of the Rights of All Migrant Workers and Members of their Families
- The Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment
- The Convention for the Protection of All Persons from Enforced Disappearance

These conventions are extensions of the general convictions contained in the Universal Declaration of Human Rights, which was adopted at the beginning of the UN's existence as an organisation in 1948. The UN Convention on the Rights of Persons with Disabilities, which forms the basis of this study circle, is one of the UN's core conventions concerning human rights.

Among many others, some of the key human rights include the right to life, the right to freedom of expression, the right to housing and food, the right of association, and the right to support for living independently within the community without discrimination.

The International Labour Organisation (ILO) is a UN agency that was included in a previous system for international collaboration – the League of Nations – that, in all other aspects, ceased to function in conjunction with the outbreak of the Second World War. Several conventions that concern labour law and certain social issues are included within the ILO system.



Sweden has ratified most of the UN's core conventions, including the UN's Convention on the Rights of Persons with Disabilities. Accordingly, the Swedish state has an obligation to fulfil its provisions, including working in various ways to ensure that the rights are afforded to each individual.

The compliance of signatory states with the various conventions is often monitored by some form of supervisory body connected to the convention – either directly or indirectly by means of an optional protocol. The UN's Committee on the Rights of Persons with Disabilities has a range of roles and mandates to monitor the compliance of the relevant states (including Sweden) with the UN Convention on the Rights of Persons with Disabilities. The objective of the work of the Committee is to support those states that have undertaken to comply with the Convention, in order to ensure the provision of access to the rights of persons with disabilities.

The Committee on the Rights of Persons with Disabilities periodically scrutinises compliance by means of a certain process that is based upon reports of the situation in the state in question and of what is being done to ensure that all obligations are implemented and all rights are provided. In addition, it can also investigate individual complaints following the conclusion of a national legal action if suspicion remains that the rights in an individual case have not been guaranteed in accordance with the requirements of the Convention. This involves complicated discussions, and suggestions for further reading include <https://lagensomverktyg.se/2020/guide-for-att-kla-ga-till-funktionsrattskommitten/> and <https://lagensomverktyg.se/2019/essa-artikel-19-och-ideologin/>.

Article 19 of the Convention on the Rights of Persons with Disabilities in full

We have translated the text of Article 19 of the Convention as follows:

Artikel 19 Rätt att leva självbestämt i samhällsgemenskapen
Konventionsstaterna erkänner lika rätt för alla personer med funktionsnedsättning att leva i samhällsgemenskapen med lika valmöjligheter som andra personer och ska vidta effektiva och ändamålsenliga åtgärder för att underlätta att personer med funktionsnedsättning fullt åtnjuter denna rätt och deras fulla inkludering och deltagande i samhällsgemenskapen, bland annat genom att säkerställa att:

- a) personer med funktionsnedsättning har möjlighet att välja sin boställningsort och var och med vem de vill leva på lika villkor som andra och inte är tvungna att bo i särskilda boendeformer,
- b) personer med funktionsnedsättning har tillgång till olika former av samhällsservice både i hemmet, knutet till boendet och till annan service i samhällsgemenskapen, bland annat sådan personlig assistans som är nödvändig för att stödja att leva och deltagande i samhällsgemenskapen och för att förhindra isolering och avskildhet från samhällsgemenskapen, samt
- c) samhällsservice och anläggningar avsedda för allmänheten är tillgängliga på lika villkor för personer med funktionsnedsättning och svarar mot deras behov.

This translation is not exactly the same as the translations used by the Swedish authorities. The Swedish Agency for Participation (MFD) has published a translation of the Convention as well as a version written in easy-to-read Swedish. These are available on the MFD website. The most significant differences concern how we have translated the title and the name of the actual right in question. The term we use can be more literally translated as “a life with self-determination within the community”, whereas the MFD translation more closely reflects the original text of the English version: “living independently and being included in the community”. We also use terminology that more closely corresponds to “personal assistance” (which is also used in the English text) instead of MFD’s “personal support”. The original text in English is as follows:

Article 19 - Living independently and being included in the community

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- (a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- (b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- (c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

About general comments

Another of the Committee's important roles is to write general comments for the various provisions and rights that are regulated in the Convention. These general comments differ from the actual Convention in that they are not legally binding for states that have ratified the Convention. This means that, although the states have a legal obligation to comply with the provisions of the Convention, they are not legally obliged to comply with the content of the general comments. The general comments do, however, constitute highly regarded interpretations and clarifications of the content of the Convention, based on the mandate given to the Committee. This mandate comes from the Committee having been created on the basis of the provisions of the Convention to which the states have become party following ratification.

The purpose of a general comment is to explain different rights and provisions in the Convention so as to clarify exactly what the states must do in order to comply with the requirements of the Convention. When reading the text of any of the articles in the Convention, it is a good idea to also read the general comments that provide more detailed explanations of the articles. The Committee has written several general comments for the Convention on the Rights of Persons with Disabilities, and each of the general comments refers to one right or aspect of the Convention. More comments are added over time. There are currently seven comments for the Convention on the Rights of Persons with Disabilities. The supervisory bodies for other conventions that have existed for longer will often have had time to create more general comments.

General Comment No 5 to Article 19 of the Convention on the Rights of Persons with Disabilities was produced in accordance with the Committee's mandate, which comes from the actual Convention.

About General Comment No 5 to Article 19 of the Convention on the Rights of Persons with Disabilities

General Comment No 5 to Article 19 clarifies many aspects of the article's text. This includes a considerably more systematic description of the background to the right to live independently with inclusion in the community than is contained in the text of the actual article. The content is described in relation to other human rights and other articles in the Convention. It provides guidance for what states must do in order to fulfil the promises they made when ratifying the Convention. It is the same Committee that has written the general comment that periodically scrutinises the state's level of compliance as well as examining individual complaints.

The original text of the general comment is written in English. A Swedish translation has been performed by MFD. The study circle can decide whether it wishes to use the English or the Swedish version of General Comment No 5. There are also certain issues with the Swedish translation that may also represent a potential subject for discussion.

One suggestion is that the study circle can discuss issues concerning the translation of the text from English to Swedish, and the risks of misinterpretation.



Examples of how study circles can be structured

Preparations for the first meeting

Once you have decided to hold a study circle devoted to self-determination, you must give thought to how you will find people to participate in the study circle. Perhaps you have already found a group of people who are interested in being involved. If not, you will need to plan how to share information about your plans for the study circle, and invite potential participants.

You could begin by creating an invitation that can be shared via different channels, containing information about the study circle and how you can be contacted. In an invitation to a study circle, you must include a brief description of what the study circle method involves. It is important that you make clear in the invitation that it is not a regular lecture or presentation, and the aim is that all members of the study circle will learn from each other as part of a mutual learning process. This will prevent participants from expecting to be part of an audience for a presentation, and perhaps feeling disappointed when they realise what being part of a study circle involves. The invitation should also include a description of the purpose of the study circle. People can feel it is more meaningful to be involved in a study circle if they have a clear idea of what it is intended to achieve. The next page features an example of the form an invitation could take.



Study Circle on Article 19 of the Convention on the Rights of Persons with Disabilities – the right to self-determination and inclusion in the community



The study circle will meet on:

Wednesday 15 April, 13:30 – 15:30

Wednesday 29 April, 13:30 – 15:30

Wednesday 13 May, 13:30 – 15:30

Friday 29 May, 13:30 – 15:30

- What does the right to self-determination and inclusion in the community really mean?
- In practical terms, how can you use Article 19 of the Convention on the Rights of Persons with Disabilities in order to access your rights?
- What is the relationship between the rights in Article 19 and the other rights included in the Convention?

If you are interested in finding the answers to these questions, you are invited to take part in a study circle, whereby people with disabilities support each other as part of a fair and equal learning process concerning Article 19 of

the Convention on the Rights of Persons with Disabilities, using exercises, discussions, and the exchanging of knowledge and experiences.

There are 10 places available in the study circle. Participants in the study circle do not require any prior knowledge of the Convention on the Rights of Persons with Disabilities.

Registrations will be accepted up to one week before the course begins.

Telephone:

Email:

The study circle will be held as part of a collaboration with the *Artikel 19 som verktyg* project, which is operated by Independent Living Institute with the support of Arvsfonden.



When you have found a group of participants and booked your first meeting, you must begin to plan how the study circle's work will take place in practice. You will need to plan an overall structure for the work of the circle, as well as for every meeting and even for the intervals between each meeting. This sounds like a great deal of planning, but it mainly involves you thinking about the resources that are available to you and planning an appropriate amount of work for both you and the study circle. Having a plan means that all the people involved will know what is to be done, and ensures that the level of work will not be excessive.

Overall structure for the work of the study circle

Begin by preparing a proposal for the overall structure of the study circle's work that links all the meetings together. This will provide an overview of what is hoped to be learned from the study circle. Below is a pyramid describing the right to a self-determined life as an example of the form the overall structure could take:



According to this pyramid, the study circle will first learn about the United Nations (UN), which developed the Convention on the Rights of Persons with Disabilities. The study circle shall then learn about the UN Committee on the Rights of Persons with Disabilities, which was established in order to monitor compliance with the Convention. The study circle shall then proceed to learn more specifically about the content of Article 19 by studying General Comment No 5, which was written by the Committee to provide a more detailed explanation of Article 19. Finally, the study circle can look in more detail at the three aspects of the right to self-determination that are raised in Article 19 (a), (b) and (c).

The first meeting

When planning the first meeting, it is a good idea to produce a structure for the implementation of the meeting, which can then be used for all subsequent meetings. This helps to create a sense of reassurance in the group, so everyone will know about the form the various meetings will take and what they can expect. Here are a few tips concerning the different topics and discussions that the study circle could cover in the first meeting:

Introductions

Begin by inviting all group members to briefly introduce themselves. It can be advisable to ask a specific question for everyone to answer, in order to avoid people worrying that they cannot think of anything to say. For example: What hobbies do you have? Where did you last go on holiday?

Brief summary of the study circle methodology

Here you can provide a brief explanation of how study circles work. You can also explain that all members of a study circle are there to learn from each other. It is therefore important that everybody actively participates in discussions and exercises. The study circle method does not work with passive participants, as it is based upon an active and continual sharing of knowledge and experiences between the group members. Also explain your role as circle leader. Ask the question: If you are not there to teach, then what is your role?





Group rules

Even for professional adults, it can be a good idea to have group rules in order to help create a sense of reassurance in the study circle. You can use these rules to explain how you will deal with certain situations that may arise within the group. Everybody will know how the discussions will be structured, as well as how they can safeguard their own personal needs and privacy in the discussions. Prepare a few suggestions for group rules before the first meeting, to make it easier for the study circle to decide on which rules the group might need. The participants can then either choose some of your proposals or suggest their own ideas.

Summary of the overall structure for the work of the study circle

Here you can explain the overall structure that you have planned for the study circle to use in its work. You will then follow all aspects of this at every meeting. It is a good idea to not rush this part, to ensure it is understood by each and every participant. You can ask follow-up questions to ensure everybody has fully understood the form the overall structure will take. You can also ask whether everybody is satisfied with the proposed structure, or if anything needs to be altered.

The objectives of the work of the study circle

This is an important discussion to ensure that the work of the study circle actually leads somewhere and that the participants get what they need from the work of the group. In the beginning, it can be a good idea to warm up with a general discussion about what people think about when they hear the words self-determination or the Convention on the Rights of Persons with Disabilities. You can also ask the participants to list the questions that come to mind when they hear these terms. Finding answers to these questions could be part of the objectives for the study circle. As with the group rules, you can prepare a few suggestions in advance to make it easier for the group to decide what they would like to be included in the objectives.

Plan for future meetings

Here you can book future meetings for the study circle. As circle leader, you can prepare a proposal for the planning of the future meetings. The participants in the circle can then decide whether or not your proposal should be changed.

Plan for the time between meetings

Here the study circle can decide whether you should also have contact with each other in the time between meetings. If you decide to have contact, the study circle must reach agreement on how and via which channels you will communicate. For example, you could decide that you (as the circle leader) will call each individual member around one week before the next meeting to make sure that everyone is coping with the study circle's work. This would also enable you to answer any questions or resolve any problems that may have arisen before the next meeting. You could also decide that the study circle should complete a task at home before every meeting, which can then be used to form the basis of the discussions at subsequent meetings.

Home tasks

If the study circle is in agreement that everyone shall complete a task at home, you can all decide what the task shall be. When you (the circle leader) prepare your proposal for a home task, it is a good idea if all the group members have slightly different tasks, so that they will all learn slightly different things. This will enable each of the participants to teach the others, instead of everybody repeating the same information. One example of a first home task could be that all members of the study circle shall read one of the articles of the Convention on the Rights of Persons with Disabilities and explain the content of the article to the rest of the group, using a practical example of how this article affects their own lives. As circle leader, you can make a selection of the same number of articles as there are group members, and ask each participant to choose one. Don't forget to ask somebody to read and explain Article 19, which will form the focus of the circle's continued studies.

Rounding off

Here all group members shall be given the opportunity to talk about their experiences of the first meeting. As circle leader, you will gain valuable information about the structure, and of whether





the general work of the study circle truly includes everybody and provides sufficient support and security to enable the work to flow. Depending on what is said during the rounding off section, you can adjust your plans for future meetings and for the work of the study circle in general.

The second and subsequent meetings

The second meeting will already be easier to plan than the first meeting, because the group will already have decided how the study circle will work, as well as having agreed on a structure for the meetings. You should now make no further changes to the structure, so that everyone knows what they can expect.

Introductions

You now probably all know who the other members of the study circle are, but it is still a good idea to ensure everybody has the chance to speak at the start, as a warm-up for continued discussions. If a new member has joined the group, they should also be given the chance to introduce themselves. Just as in the first meeting, you can make things easier by asking a specific question, so that nobody struggles to find something to say.

Brief summary of the study circle methodology

If any new member has joined the group, you will need to explain how the study circle method works again, so that everyone understands. If everybody has already heard your explanation, you can initiate a brief discussion of the method so that everyone knows what is expected of them.

Group rules

Here you can run through the group rules that were agreed at the first meeting, as a reminder. You can also hold a brief discussion if somebody has thought of something else that perhaps needs to be added.

The objectives of the work of the study circle

As with the group rules, you can run through the objectives again, as a reminder. Perhaps somebody has thought of something new that needs to be added.

Summary of the overall structure for the work of the study circle

Explain the overall structure again if there are any new members in the group. If everybody has already heard your explanation, you can ask a few follow-up questions and repeat what you talked about at the first meeting. At the third and subsequent meetings, you can use this overall structure as the basis for a brief discussion as a warm-up for the current meeting. You can ask each member to explain one feature of the overall structure.

Following-up of home tasks

This point only applies if the study circle has agreed that participants will complete home tasks before each meeting. Now everyone will have the chance to share what they have learned from the home task, as well as learning from the others. A person who talks about Article 19 will teach the others about the meaning of the right to self-determination.

Exercises

Here you can perform one of the exercises in the ‘Eight guidelines for different elements of the study circle’ section, which begins on page 31. The first exercise (A unique article within the system of human rights) could be a logical follow-up to the discussion after the completed home task. You can ask all participants to talk about how the article they have read about relates to Article 19 of the Convention on the Rights of Persons with Disabilities. The person who read about Article 19 can reflect on the others’ answers.

Discussion about General Comment No 5

Now that you have begun to look in more detail at the content of Article 19, it is a good idea to look at General Comment No 5 in order to find more information about the right to self-determination. Think about what you all remember about the general comment from when you discussed the overall structure for the work of the study circle. This will verify that you all understand what a general comment is, its purpose and why you need to read it. Share the text of the general comment, and hold a discussion on its logic. You can run through the table of contents to see how





the general comment is structured, and discuss the different sections so that everybody understands what they include. If you look at the section concerning the obligations of states, you can discuss the meaning of the term ‘obligations of states parties’ in the general comment.

The next home task

Here the study circle can decide upon the task that all members shall complete before the next meeting. Now that you have begun to look more closely at General Comment No 5, it could be a good idea to read part of it at home. For example, you could ask each participant to read one of the paragraphs in the section about the obligations of states, and prepare to explain the content of this paragraph to the other members of the study circle. Each participant can also talk about what needs to be done in their local municipality in accordance with the state’s obligation that they have read about.

The plan for the continued work of the study circle

Run through the plan for the study circle’s continued work, and verify that it works for all participants and that they are all keeping up and remember what has been planned. Talk about what has been planned for future meetings, and of the plans for the times between the meetings.

Rounding off

Discuss everybody’s experiences of this meeting, and what they all think about the work of the study circle so far. As circle leader, you can use this information to refine the plans for continued work, if necessary.

Eight guidelines for different elements of the study circle

1. A unique article within the system of human rights

All people are born with inherent dignity, and equal and inalienable rights. Human rights are universal and apply to every human being.

The UN's Declaration of Human Rights dates from 1948. The rights contained in the Declaration have been transferred to various conventions, which, unlike the Declaration, are legally binding for those states that are signatories.

There are two main conventions from 1966. These are complemented by separate conventions for different groups, in order to guarantee that all people truly have access to their human rights.

The Convention on the Rights of Persons with Disabilities was approved in 2006 and became applicable as a legal document in Sweden in 2009.

For each convention, the UN appoints a supervisory committee that receives complaints from people who believe that their rights have not been fulfilled. The committees also issue general comments to the various articles contained in the conventions. The general comments are not legally binding, but they do explain how the article is to be used in practice.

Exercise

Each participant (or pair of participants, in groups of more than 5) chooses one of the following articles in the Convention on the Rights of Persons with Disabilities. Consider how it relates to Article 19:

- Equal recognition before the law – Article 12
- Accessibility – Article 9
- Education – Article 24
- Equality and non-discrimination – Article 5
- Participation with persons with disabilities in the implementation and monitoring of the Convention – Article 4:3/33:3



Discussion questions

- Which fundamental principles form the basis for human rights?
- What has the Convention on the Rights of Persons with Disabilities given to the world?
- What does it mean that the Convention on the Rights of Persons with Disabilities combines civil and social/economic/cultural rights? How does it then also relate to the Convention on the Rights of the Child; economic, social and cultural rights; and Agenda 2030?
- Which societal problems lay behind Article 19? (read in GC5)

2. Being the principal person in my own life

All individuals have the right to influence what happens in their lives – the right to the same choices and to exert control over their lives as other members of society have. The right to a self-determined life (living independently) concerns the individual's right to decide how they want to live and develop without being obstructed or denied the opportunities for this, and to have control over what happens in their own life.

Article 19 concerns (for example) the freedom to choose a home and town of residence, the right to live independently with inclusion within the community, the right to personally adapted support and service, and the right of access to general societal services. It also concerns the right to decide one's own identity – about who one is, one's lifestyle and cultural affiliation.

Exercise

Choose one of the following two exercises:

- Each participant shall think about an occasion on which they did not feel that they were free to make their own choices. Discuss these in groups of two or three. Then let each group talk about some of the issues that emerged.
- Each participant shall choose a keyword from Article 19, and spend 15 minutes quietly preparing a mini-presentation based on this word. Make use of GC5 to explain your word.

Discussion questions

- What is meant by the right to self-determination and inclusion in the community?
- What kind of knowledge and resources do you need in order to exercise your rights? What prevents you from using these resources?
- Article 19 includes the right to autonomy in one's own life and participation within the community. This shall be realised by (among other things) what is stipulated in points (a), (b) and (c) below.
- What does having an administrator or guardian involve?
- What is the difference between substituted decision-making and supported decision-making?

3. The right to live as one pleases

Article 19 ensures the right to decide where, how and with whom one shall live. Persons with disabilities have the right to make decisions concerning their living conditions on an equal basis as others, and shall not be referred to special residential forms.

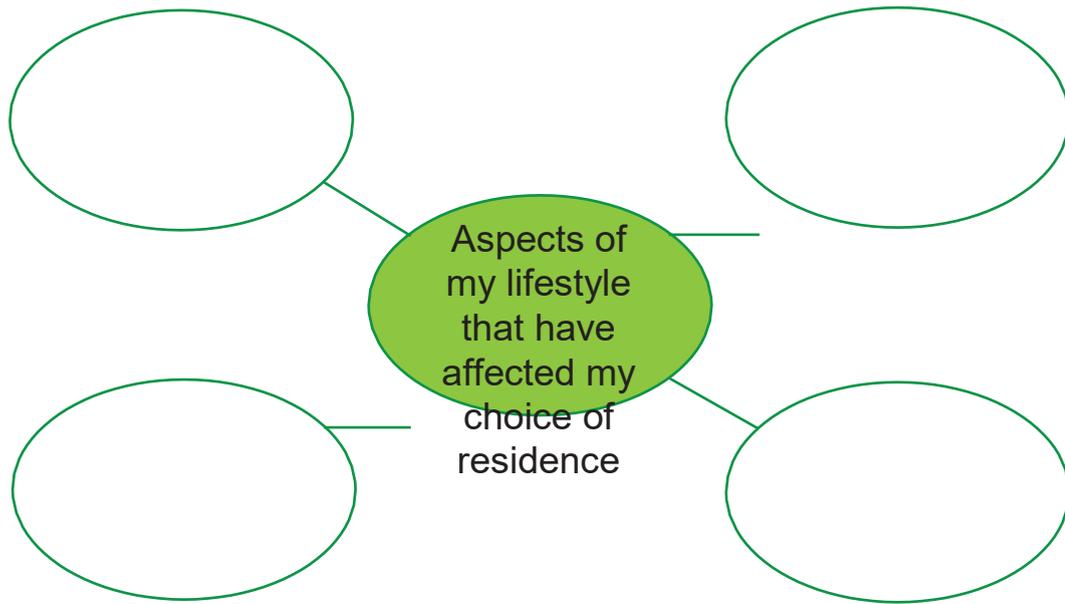
The right to decide where and with whom one shall live is a civic and political right. It shall therefore be ensured directly by the state, following accession to the Convention.

Residences are interconnected with other aspects of life. GC5 also talks about lifestyle and the right to decide one's own identity.

Exercise

Think about how your lifestyle has affected your choice of residence. Draw a mind-map showing all the aspects of your lifestyle that have affected your choice of residence. You can use the diagram on the next page as the basis for your mind-map.





Discussion questions

- What influence do we have over whom we live with?
- Which specific examples can you find in GC5 of what the right to choose one's residence actually involves? Can you come up with any others?
 - » Discuss (e.g.) food, curfew and bedtimes, personal possessions/ornaments, pets, etc.
- What is important for your personal self-expression?
- Discuss things such as clothes, musical tastes, socialising, etc.

4. The right to good support

According to GC5, good support is based on respect for inherent dignity, and provides the tools for the exercising of choice and control over one's own life. The support shall be personally designed in accordance with the individual's wishes and those needs that arise due to obstacles in society. Consideration shall be shown to the fact that activities – and thereby needs – change with time. The support shall not be based on the interests of authorities or the providers of the support. The right to individual person-based forms of support, such as personal assistance, is an economic and social right, which means that it is to be progressively implemented by the state. There is currently a shortage of investigations, statistics and information concerning which forms of support are available and which ones work.

Exercise

Each participant shall look for a short quote from GC5 that concerns support. Write down your quotes, and post them on the wall. Add stickers to vote for the different quotes.

Discussion questions

- What is meant by support that is based on respect for inherent dignity?
- How shall personal assistance work, in accordance with General Comment No 5?
- How shall needs assessment be performed, in accordance with General Comment No 5?
- Is any other support available, apart from that provided by authorities?
- What is good support from family and relatives?
- What is poor support from family and relatives, with regard to the opportunity to participate in the community?
- Is there any support that inhibits one's own freedom?
- What is good support to increase participation in the community?
- What is good support to prevent loneliness and isolation?
- How can people with disabilities help each other, and how can they hinder each other?

5. Being involved in the community

Everyone has the freedom to choose and the right to live independently with inclusion in the community. People with disabilities have the right to access general services in the same way as others. This works if transport, information, housing, etc. have been designed with accessibility in mind from the beginning, in accordance with the principle of universal design. This means that all products, environments, programmes and services must be designed to ensure they can be used by as many people as possible. The societal changes that are required in order to ensure the accessibility and usability of society's infrastructure should be implemented gradually.

Exercise

Design an urban neighbourhood where different types of people will live. Discuss your various ideas of dream homes and wishes for the various establishments – gyms, libraries, places of worship, etc. How should these





be designed to ensure they will be accessible for all? Sketch your designs on large sheets of paper, or build models.

Discussion questions

- Is social media inclusive or exclusive?
- How could sports organisations be designed to ensure that everyone can be involved?
- What are the implications of universal design for:
 - » Schools
 - » Work
 - » Housing

6. What is meant by institutions?

When General Comment No 5 mentions institutions, it is not referring to a physical institution but rather things such as segregation, and restrictions on freedom, choice and autonomous control in everyday decisions and other aspects of life. The fundamental human rights and freedoms are not found in institutions. Segregated housing or the disproportionate presence of people with disabilities in the same environment are obstacles to freedom and control. By understanding what is NOT accepted in Article 19, it becomes clear what the Article is actually demanding.

Exercise

Choose one of the following two exercises:

- On different pieces of paper, each individual shall write down a few synonyms for freedom of choice and autonomous control, as well as a few words to describe their opposites. Lay the pieces of paper on the floor, and position yourself according to how you relate to each of these today – perhaps you feel somewhere between two of them?
- Invite somebody to talk about what it feels like to live in an institution. Finding that person can be a rewarding process. It could even be somebody who already belongs to the group.

Discussion questions

- What can the denial of freedom or autonomous control lead to – both in the short and the long term?
- What is GC5's view of group housing and satellite housing?
- What is GC5's view of how children should live?
- How well does personal assistance work in comparison to staffed group housing?
- What influence do you have over who shall work as an assistant or other personnel?

7. How can we change society?

States, county councils and municipalities are responsible for ensuring that all people are able to benefit from their rights, and facilitate full participation. It must not, for example, be more expensive to live with a disability, and the state and municipal governments must ensure that people can afford to live within the community and not be forced into an institution. According to Article 19, the withdrawal of previously granted support is discriminatory. Cost-effectiveness is a good thing, but it must not be achieved at the expense of human rights. Financial support can instead be steered to prevent the building of institutions or other segregation-based solutions.

Exercise

Find out how the 'Inclusive Equality' method works, in accordance with GC5. Conduct a mini-investigation into what municipalities say about a certain issue, and the views of different organisations and associations concerning a certain societal support in your municipality/region. Brainstorm different proposals for improvement, and rank them by order of priority. Draw up an action plan, and contact the associations/organisations in question to suggest a certain action or statement.

Discussion questions

- What form could a good information campaign concerning the rights in Article 19 take?
- How should personnel and employees working with support be trained in Article 19?
- Is there a need for more statistics and knowledge about the situation for persons with disabilities?



8. Pursuing one's own rights

People with disabilities shall, with the help of their organisations, be involved and monitor that states follow and realise the Convention on the Rights of Persons with Disabilities.

Legislation and conventions represent legal tools that can be used if and when our own rights are violated. The denial of reasonable accessibility measures is a form of discrimination, and action can be taken in accordance with Sweden's Discrimination Act.

Exercise

Person X has been placed into an institution against their will. Construct a plan to help Person X to pursue their own rights following the legal path all the way to the UN.

Discussion questions

- What kind of protections are provided by declarations, conventions and legislation?
- What prevents you from benefiting from your rights?
- What do you need in order to benefit from your rights?
- When can you contact the supervisory committee for the Convention on the Rights of Persons with Disabilities?
- How can you contribute to the monitoring of Article 19?

Annex 1: Discussion about the General Comment for Article 19

The purpose of the General Comment is to help the states to implement Article 19 and to fulfil their obligations in accordance with the Convention.

Article 19 includes:

1. the right to an independent life (individual dimension)
2. the right to inclusion within the community (social dimension)

These rights are applicable irrespective of intellectual capability, ability/disability or support needs – i.e. it also includes those persons with intellectual impairment.

Other General Comments – and translation into Swedish

3.	Equal recognition before the law	Art 12	SWE
4.	Accessibility	Art 9	SWE
5.	Women and girls with disabilities	Art 6	SWE
6.	Right to inclusive education	Art 24	SWE
7.	Right to independent living	Art 19	SWE
8.	Equality and non-discrimination	Art 5	SWE
9.	Participation with persons with disabilities in the implementation and monitoring of the Convention	Art 4:3/33:3	2019



Contents

The General Comment contains 97 paragraphs:

1. **Introduction**
Paragraphs 1–15
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Paragraphs 24–27 C. Article 19 (a)
Paragraphs 28–31 D. Article 19 (b)
Paragraphs 32–37 E. Article 19 (c)
Paragraph 38 F. Core elements
3. **Obligations of States parties**
Paragraphs 39–46
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Paragraphs 50–53 B. Obligation to protect
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4. **Relationship with other provisions of the Convention**
Paragraphs 69–96
5. **Implementation at the national level**
Paragraph 97

Introduction (1 to 15) in summary:

1. Background of people with disabilities having been denied their rights, and that society has built institutions.
2. The basis of Article 19 is the core human rights principle that all human beings are born equal in dignity and rights.
3. We are both subjects of rights and rights holders. Connections to the general principles of Article 3 of the Convention.
4. Persons with disabilities have asserted their own empowering forms of support such as personal assistance, and have demanded universal design principles.
5. Article 19 is a cost-effective mechanism to combat stigma,

segregation and discrimination that can lead to violence, exploitation and abuse.

6. Article 19 has a broad range, is intersectional, and is integral to the full implementation of the Convention.
7. Article 19 entails the progressive realisation of economic, civil, social and cultural rights.
8. Article 19 reflects cultural diversity, and is not biased towards certain cultural norms and values.
9. Deeply rooted in Article 29.1 of the Universal Declaration of Human Rights and Articles 11 and 12 of the International Covenant on Economic, Social and Cultural Rights.
10. Connection to the Convention on the Elimination of All Forms of Discrimination against Women – e.g. Article 15.4 on the movement of persons and the freedom to choose their residence and domicile.
11. Connection to the Convention on the Rights of the Child, including Article 20 on the right to protection and assistance, as well as alternative care, although this is discriminatory if provided on the grounds of disability.
12. Connection to Article 23.1 of the Convention on the Rights of the Child concerning the placement of children in institutions and the need for deinstitutionalisation to ensure a life in dignity with self-reliance and participation.
13. General Comment No 5 for the Committee on Economic, Social and Cultural Rights regards segregation and isolation as discrimination. The right to an adequate standard of living in Article 11 of the Committee on Economic, Social and Cultural Rights applies to support services and assistive devices and technologies.
14. Connection to the UN's New Urban Agenda (Habitat III) on housing and sustainable urban development, and Agenda 2030 for sustainable development.
15. Remaining barriers to the implementation of Article 19:
 - a) Denial of legal capacity – e.g. by substitute decision-making.
 - b) Inadequacy of support and protection schemes for ensuring independent living within the community.
 - c) Inadequacy of personal assistance and individualised support.
 - d) Institutionalisation and forced treatment.



- 
- e) Lack of deinstitutionalisation and investment in new institutions.
 - f) Negative attitudes, stigma and stereotypes preventing inclusion and assistance.
 - g) Misconceptions about the right to living independently within the community.
 - h) Lack of services and facilities, such as transport, healthcare, schools, public spaces, housing, theatres, cinemas, goods and services, and public buildings.
 - i) Lack of adequate monitoring mechanisms for ensuring the implementation of Article 19, such as the non-participation of organisations representing persons with disabilities.
 - j) Lack of disability perspectives in state or municipal budget allocations.
 - k) Decentralisation that results in differences and inequalities between local authorities.

The following concepts are defined in paragraph 16:

- Independent living
- Inclusion in the community
- Independent living arrangements
- Personal assistance

Principles in Article 19 (according to General Comment No 5):

- Everyone has the freedom to choose, and the right to live independently with inclusion in the community.
- The fundamental human rights and freedoms are not found in institutions.
- Support shall be based on respect for inherent dignity.

Core values in Article 19:

- Choice
- Personal control

Central idea of Article 19:

To decide where, how and with whom one shall live, and participate within the community.

Key elements in Article 19 in accordance with paragraph 38 (summary):

- a) The right to legal capacity, and the right to decide where, how and with whom one shall live.
- b) Non-discrimination in access to housing by adopting building regulations that ensure new and renovated housing are accessible.
- c) Action plan for formal support, so that informal support (e.g. from the family) is not the only option.
- d) Act on laws and rules to ensure the achievement of equality. Access to social media and information and communication technologies, in accordance with the principle of universal design.
- e) Support and societal services that are personalised and not shared with others.
- f) Ensuring of non-retrogression in achieving the content of Article 19, unless duly justified and in accordance with international law.
- g) Collection of quantitative and qualitative data concerning people with disabilities, including those living in institutions.
- h) Securing of funding for inclusive and accessible independent living services.





Examples of which decisions one has the right to make:

- what one shall eat
- when one shall sleep
- whether to be at home or outdoors
- daily activities
- tables with or without a tablecloth
- pets

Search for more examples in the General Comment!

The right to decide one's own identity:

- who one is
- whether to be alone or not
- lifestyle
- cultural affiliation
- HBTQ mentioned

Search for more aspects in the General Comment!

What is meant by institutions?

- Segregated housing that denies freedom or autonomous control in everyday decisions and other aspects of life.
- Disproportionate presence of people with disabilities in the same environment.
- Not a building – instead, a question of choice. For example:
 - » non-sharing of assistants (unless they want to)
 - » influence over with whom one lives or who acts as an assistant
 - » not the same activities for all

What is meant by participation in the community?

- **Objective:** Access to the same services as the general population – education, work, social media, sports, museums, libraries, etc.
- **Basis:** General accessibility – universal design
- **Support:** Shall be a tool for choice and control.
 - » Individually designed for the individual – not for the support-provider
 - » Needs-assessment according to the person's will (activities may vary)

Advice for states and municipalities, in accordance with General Comment No 5:

- States and municipalities are responsible for ensuring that all people are able to benefit from their rights and facilitate full participation.
- Family members and third parties may not intervene in independence or undermine opportunities for participation in society.
- Help families to support family members with disabilities in order to realise the right to independent living – e.g. by means of advice or support groups.

Examples of what the state shall do, in accordance with General Comment No 5 (part 3):

- Provide people with legal means
- Campaigns to raise awareness
- Easily understandable information about Article 19
- Training of personnel for independent living
- Provide investigations, statistics and information about support
- Monitoring systems for the implementation of Article 19, but also monitoring of institutions and support forms



Measures that should be adopted by the state, in accordance with paragraph 97 (summary):

- (a) Repeal laws that inhibit the choice of where, how and with whom one will live, including the right to not be confined on the basis of a disability.
- (b) Enact and enforce laws, standards, etc. in order to make local communities and communication accessible for persons with disabilities.
- (c) Ensure that social protection programmes meet the requirements of all persons with disabilities on an equal basis with others.
- (d) Introduce the principle of universal design for physical and virtual space in policies and legislation, as well as in the monitoring of implementation. Review building codes and practices to ensure they comply with accessibility requirements.
- (e) Provide persons with disabilities with their substantive and procedural rights.
- (f) Inform rights-holders in such a way that they can understand and increase their empowerment so that they are able to enforce their rights.
- (g) Plan and allocate funds for deinstitutionalisation and the elimination of isolation and segregation – particularly for persons with psychosocial and/or intellectual disabilities and for children.
- (h) Increase awareness of negative attitudes and stereotypes, and develop individualised and accessible mainstream services.
- (i) Ensure the participation of persons with disabilities in the transformation and design of support services and in deinstitutionalisation strategies.
- (j) Guarantee housing, built environments, public spaces and transport that are accessible and affordable, and implement sanctions for violations of this by public or private authorities.
- (k) Support services such as personal assistance, guides and interpreters shall be user-led.
- (l) Design tendering processes to ensure support for persons with disabilities facilitates living independently in the community.

- (m) Monitoring of institutions, plans for deinstitutionalisation and implementation, in accordance with the provisions of independent monitoring.
- (n) Monitoring of the implementation of Article 19 in full consultation with persons with disabilities and their representative organisations.



Annex 2: Examples of agendas from a self-determination circle with four meetings

The first meeting: Article 19 study circle

Gothenburg: 05/04/2020 13:30 – 15:30

13:30 Who are we?

Introductions: Talk about your hobby
What should we do about a break?

13:45 The study circle method

How does the study circle method work?
The roles of the circle leader and of the participants

14:00 Suggestions for group rules

- ▶ We actively listen to each other
- ▶ Everybody has the chance to speak as much or as little as they want to
- ▶ If you would rather not answer, just say “Pass”
- ▶ Personal information shared in the group stays in the group

Do we need any additional rules for our group?

14:15 Brief run-through: the structure of the Convention on the Rights of Persons with Disabilities

14:30 Break 10 min.

14:40 The objectives of the work of the study circle

Warm-up discussion

What do we think about when we hear the words “Convention on the Rights of Persons with Disabilities”? Everybody shares their thoughts, opinions and any questions that arise. How was I able to contribute to the study circle?

Exercise

Together, we write down the objectives of the work of the study circle. Suggestion:

- ▶ We shall learn more about the Convention’s rights, focusing on Article 19.
- ▶ We shall learn more about how the Convention works in Sweden.
- ▶ We shall learn more about how we ourselves can use the Convention.
- ▶ Sharing of experiences.

15:00 The plan for future meetings

Booking of dates/times for future meetings. Suggestion:

- ▶ **Wednesday 29/04/2020:** What rights does the Convention actually give, and why is Article 19 worthy of special focus?
- ▶ **Wednesday 13/05/2020:** How does the Convention work in Sweden, and how can I apply it to my life in practice?
- ▶ **Wednesday 03/06/2020:** Rounding off

15:10 Home task

Everybody shall read one of the Convention’s articles, prepare to explain what they have read, and provide practical examples of how the right could affect their own life.

15:20 Rounding off

Thoughts about the first meeting of the study circle.



The second meeting: Article 19 study circle

What rights does the Convention actually give, and why is Article 19 worthy of special focus?

Gothenburg: 29/04/2020 13:30 – 15:30

13:30 How do we all feel?

Introductions: Talk about something that has gone well for you.

13:45 The study circle method

How does the study circle method work? The roles of the circle leader and of the participants.

13:50 Group rules and the objectives of the work of the study circle

- ▶ We read through the group rules that we agreed on at the previous meeting. Is there anything in the group rules that we need to change?
- ▶ We read through the objectives of the work of the study circle. Is there anything we need to change?

14:05 Brief run-through: the structure of the Convention on the Rights of Persons with Disabilities

Together, we look at the overall picture of the Convention's structure.

14:15 Break 10 min.

14:25 Follow-up of the home task

Everybody talks about the article of the Convention that they have read, and explains to the others which rights it involves. Everybody then gives practical examples of how the rights in this article could affect their own life.

14:45 Exercise: The connection between Article 19 and the other articles of the Convention

Everybody talks about how they think the article they have read connects to Article 19.

15:00 Brief run-through: General Comment

Together, we look at the Swedish text of General Comment No 5, specifically focusing on the part concerning the obligations of the Convention's states.

15:05 Home task

Everybody shall read one paragraph about the obligations of states in General Comment No 5.

- ▶ Talk about the paragraph in the General Comment that you have read, and explain which other obligations for the Convention's states it involves.
- ▶ What needs to be done in your local municipality, in accordance with the obligations you have read about?

15:15 The plan for future meetings

Booking of dates/times for future meetings. Suggestion:

- ▶ **Wednesday 13/05/2020:** How does the Convention work in Sweden, and how can I apply it to my life in practice?
- ▶ **Wednesday 03/06/2020:** Rounding off

15:20 Rounding off

Thoughts about the first meeting of the study circle.



The third meeting: Article 19 study circle

How does the Convention work in Sweden, and how can I apply it to my life in practice?

Gothenburg: 13/05/2020 13:30 – 15:30

13:30 How do we all feel?

13:50 Group rules and the objectives of the work of the study circle

We read through the group rules that we agreed on at the first meeting. We read through the objectives of the work of the study circle.

14:00 Brief run-through: the structure of the Convention on the Rights of Persons with Disabilities

Together, we look at the overall picture of the Convention's structure.

14:10 Follow-up of the home task

Everybody talks about the paragraph in General Comment No 5 that they have read, and explains to the others which obligations for the Convention's states it mentions.

Everybody answers the question: What needs to be done in your local municipality, in accordance with the obligations you have read about?

14:30 Break 10 min.

14:40 Discussion: The Convention on the Rights of Persons with Disabilities in Sweden's courts

15:05 Home task

Read Article 19 of the Convention on the Rights of Persons with Disabilities.

1. Think of a change that would be needed to improve your personal access to your rights in accordance with Article 19.
2. Think of how you could argue for this change on the basis of Article 19.

If you want, you can use arguments from the whole of the Convention and from General Comment No 5.

15:15 The plan for future meetings

Booking of dates/times for future meetings. Suggestion:

- ▶ Wednesday 03/06/2020: Rounding off

15:20 Rounding off

Thoughts about this meeting of the study circle.



The fourth meeting: Article 19 study circle

Gothenburg: 03/06/2020 13:30 – 15:30

13:30 How do we all feel?

13:50 Group rules and the objectives of the work of the study circle

We read through the group rules that we agreed on at the first meeting. We read through the objectives of the work of the study circle.

14:00 Brief run-through: the structure of the Convention on the Rights of Persons with Disabilities

Together, we look at the overall picture of the Convention's structure.

14:10 Follow-up of the home task

Everybody has read Article 19 of the Convention, and answers the following questions:

- ▶ Think of a change that would be needed to improve your personal access to your rights in accordance with Article 19.
- ▶ Think of how you could argue for this change on the basis of Article 19.

14:30 Break 10 min.

14:40 Discussion: the practical use of the Convention on the Rights of Persons with Disabilities and General Comment No 5

How could we use arguments that we can find in the Convention and the General Comment?

1. Personal level
2. Political interest level

15:00 Discussion: The Convention on the Rights of Persons with Disabilities in Sweden's courts

15:10 Rounding off

- ▶ Reflections on the work of the study circle.
- ▶ Is there anything else we would want to follow up?





ANNEX 3: Suggestions for group rules

Group rules:

- Duty of confidentiality
- Providing notification if you will be late
- Mutual respect
- Say “Pass” if you’d prefer to not answer
- Leave room for each other in discussions

